

# Identifiers

CSTE DSWG Data Element Specific Team

7/19/2024



Council of State and Territorial Epidemiologists

# CSTE Data Standardization Workgroup Meeting



***Please mute phone/ headset/ computer audio!***

## Agenda

- Welcome & Announcements
- Identifier Structure
- Specimen ID
- Birthing Parent-Infant Linkage?
- Next Steps
- Wrap-Up & Adjourn

# Meeting ground rules



- Discussion Guidelines
  - "Raise" your hand
  - Use the chat to provide feedback and ask questions
  - When called, state your name and affiliation
  - Stay on point, be brief, and within the context of the discussion in progress
  - 80/20 consensus
  - Co-Chairs/moderators' prerogative to move the discussion forward as needed
    - [Post-meeting input form](#) is always available for additional comment
    - Be courteous and be open to new ideas

## **Active participation encouraged for all!**

- Chats, voting, comments, etc.
- Includes STLT jurisdictions + CDC Programs + CSTE, etc.

# Core Data: In Scope for DSWG CSTE

- Identify core data elements for surveillance **for transmission to CDC**
  - For situational awareness or routine, cross-condition case surveillance
  - For case-based surveillance (not syndromic, not aggregate reporting)
  - Within *selected* data classes (e.g., hospitalization, travel history) that are used for multiple conditions
- Identify common definitions, value sets/code sets, structure, and interpretation notes for those core data elements
- Recommend best practices for how selected data elements are collected, structured or populated within PHA surveillance systems, if/when that will affect the interpretation of the data transmitted to CDC

## Core for CDC Transmission ≠ Required

Even if a data element or class is identified as appropriate for transmission to CDC, this does *not* mean we need to fill in or send an answer for every core element for every case!

- It is okay to leave the data field as blank or Unknown if the information is not available, not a priority, or not useful for particular conditions.

Data elements and data classes should be considered for core if they are relevant for many conditions

- There is no set number that defines "many".
- Would you rather see the element in (for example) a GenV3 MMG? or in the applicable disease-specific MMGs?

# Identifier Structure



# What does it mean for an identifier to be core?



A core identifier should be something that would be capable of being transmitted across conditions when needed.

- All cases require a unique ID to be identified as a unique case. (~~Local Record ID~~ Case ID)
- Something like an “Outbreak ID” would rarely be present, but if core then a jurisdiction should be capable of capturing/sending that field across conditions.
- Core = Will be prepared to utilize it across conditions as needed. Minimum value set/set of elements for what states are ready to send.

# Potential Identifier Structure



- After the last call, the structure has been modified to remove "identifier assigner".
  - Would create the "parent-child-grandchild" scenario in some use cases.
  - Given our current minimum value set for identifiers, it is not needed for core.

| Data Element (DE) Name | DE Identifier Sent in HL7 Message | Data Element Description  | Data Type |
|------------------------|-----------------------------------|---------------------------|-----------|
| Identifier Type        | TBD                               | Description of identifier | Coded     |
| Identifier Value       | TBD                               | Unique identifier value   | Text      |

```
OBX|nn|CWE|TBD^Identifier Type^PHINQUESTION|1|TBD^NORS ID^PHINQUESTION|||||F
OBX|nn|ST|TBD^Identifier Value^PHINQUESTION|1|EIP123456|||||F
```

# Minimum Set of Identifiers



| Identifier Type                     | Data Element Description                                                                                                   |
|-------------------------------------|----------------------------------------------------------------------------------------------------------------------------|
| Legacy Case Identifier              | <del>Links current case notifications to case notifications submitted by a previous system.</del>                          |
| CDC-assigned Case ID                | A CDC-assigned ID for use in situations such as an emergency response.<br><i>(Like DCIPHER ID for mpox.)</i>               |
| Outbreak ID – Jurisdiction-assigned | A jurisdiction-assigned ID for an identified outbreak.<br><i>(Replacement of Case Outbreak Name.)</i>                      |
| NORS ID                             | The outbreak ID from CDC's National Outbreak Reporting System (NORS) for the outbreak this case report is associated with. |

Legacy Case ID will be noted as an ID CDC needs to support, but only used by jurisdictions undergoing transitions.

# Polling process



- Poll questions will be shown first on a slide before poll opens
  - Opportunity for clarifications & questions
- Feel free to abstain if you don't have a preference or don't feel strongly
- Opportunity for limited discussion on questions with a big split

# Poll 1 – Identifier Structure



Do you support the repeating group structure for identifiers as shown below?

*Excluding Person (local subject) ID and Case (local record) ID.*

- Yes, I can live with it.
- No, prefer discrete data elements.

| Data Element (DE) Name | DE Identifier Sent in HL7 Message | Data Element Description  | Data Type |
|------------------------|-----------------------------------|---------------------------|-----------|
| Identifier Type        | TBD                               | Description of identifier | Coded     |
| Identifier Value       | TBD                               | Unique identifier value   | Text      |

# Poll 2 – Minimum Value Set



Do you support the below identifiers as our "minimum value set" for identifiers?

- Yes, I can live with it.
- No.

| Identifier Type                     | Data Element Description                                                                                                   |
|-------------------------------------|----------------------------------------------------------------------------------------------------------------------------|
| CDC-assigned Case ID                | A CDC-assigned ID for use in situations such as an emergency response.                                                     |
| Outbreak ID – Jurisdiction-assigned | A jurisdiction-assigned ID for an identified outbreak.                                                                     |
| NORS ID                             | The outbreak ID from CDC's National Outbreak Reporting System (NORS) for the outbreak this case report is associated with. |

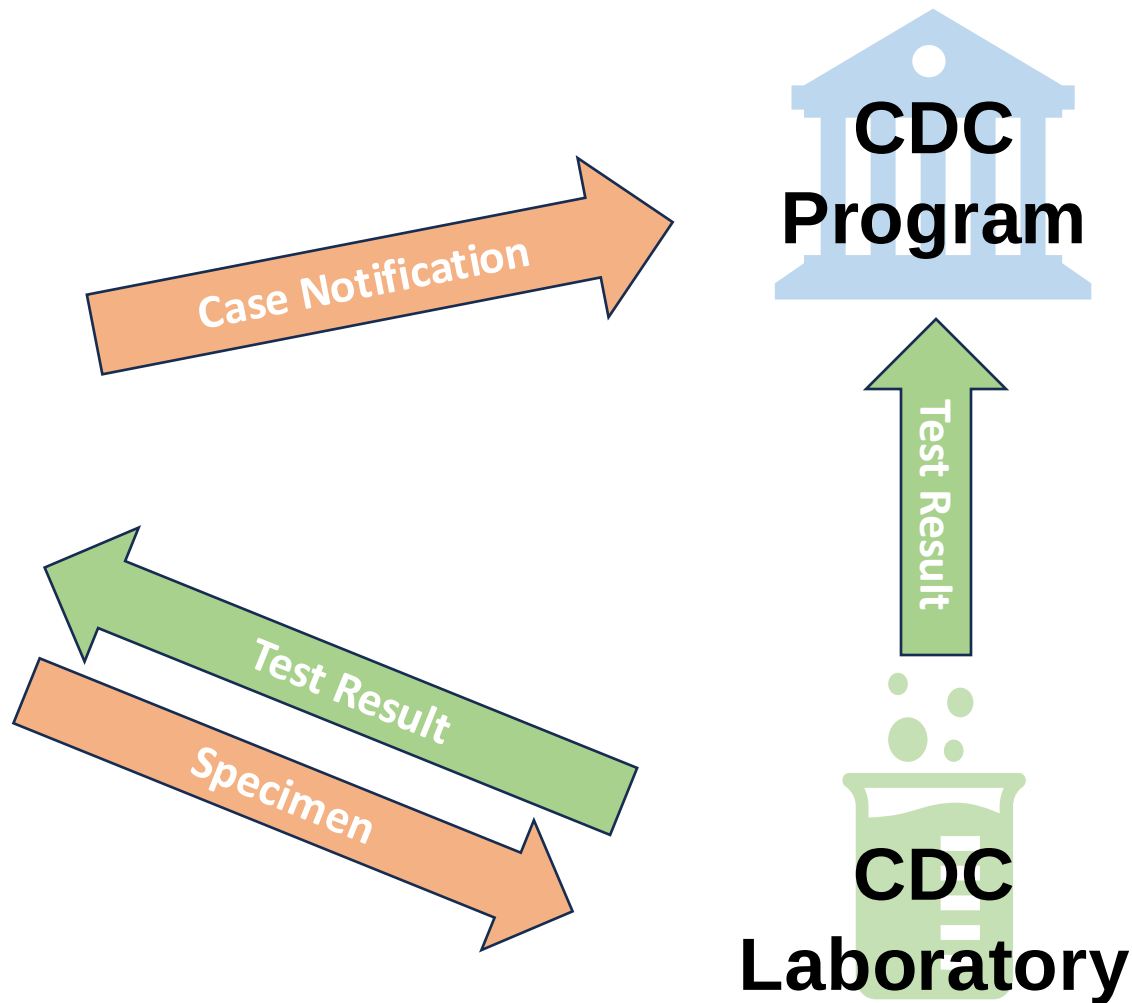
# Specimen ID



# CDC Laboratory Results



**Jurisdiction**



# Case notification – Specimen linkage



Specimens are sent to CDC for testing with information in 50.34 form, Global File Accessioning Template (GFAT), or CDC Specimen Test Order and Reporting (CSTOR)

- Data elements include
  - Patient Name
  - Public Health Patient ID, Specimen ID
  - Original Submitter Patient ID, Specimen ID
  - Intermediate Submitter Patient ID, Specimen ID

# Example: CDC Laboratory Result (PDF)



## Centers for Disease Control and Prevention Antimicrobial Resistance and Characterization Laboratory

Patient Name: **None Provided**

Sex:

Birthdate:

Age:

Date of Onset:

### Original Submitter IDs

Patient ID: **Direct Observation**

Alt. Patient ID:

Specimen ID: **DO-01**

Alt. Specimen ID:

CDC Specimen ID:



CDC Unique ID:



Suspected Agent: Gram-negative rod

### **Xpert Carba-R RT-PCR Assay**

### **Interpretation**

blaIMP detection by Xpert PCR<sup>\*</sup>

Negative

blaVIM detection by Xpert PCR

Negative

blaNDM detection by Xpert PCR

Negative

blaKPC detection by Xpert PCR

Positive

blaOXA-48-like detection by Xpert PCR

Negative

<sup>\*</sup> Not all blaIMP-variants have been evaluated with the Xpert Carba-R Assay. The Xpert Carba-R Assay can detect blaIMP-1, -2, -4, -6, -10, and -11. Please see package insert for details ([www.cepheid.com](http://www.cepheid.com)).

# Case Notifications to CDC



Current Malaria v1.0 MMG:

| Data Element (DE) Name                      | Data Element Description                                                                             | Data Type |
|---------------------------------------------|------------------------------------------------------------------------------------------------------|-----------|
| Specimen Sent to CDC                        | Was specimen(s) sent to CDC?                                                                         | Coded     |
| <b>START: Specimen Type Repeating Group</b> |                                                                                                      |           |
| Specimen Type(s) Sent to CDC                | Type(s) of specimen sent to CDC                                                                      | Coded     |
| CSID                                        | CDC specimen ID number from the 50.34 submission form. Example format (10-digit number): 3000123456. | Text      |

# Specimen ID



Will be discussed in the Lab DEST to be part of lab template/epi lab block.

| Date Element Name | Date Element Description                                                        | Implementation Note                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|-------------------|---------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Specimen ID       | A laboratory generated number that identifies the specimen related to this test | <p>If test conducted at CDC, populate this field with the CDC specimen ID. The CDC specimen ID is a 10-digit number (Example: 3000123456) and can be found in ORC -3.1.1, OBR-3.1.1, or SPM-2.2.1 of CDC's ELR message. It can also be found on page 2 of the PDF result returned in CSTOR.</p> <p>If the CDC Specimen ID is not available and the specimen was sent to CDC from the public health lab, populate this field with the public health lab specimen ID, which can be found in ORC-2.1.1, OBR-2.1.1, or SPM-2.1.1 of CDC's ELR message. It can also be found on page 1 of the PDF result returned in CSTOR.</p> |

# Specimen ID



Potentially can also be captured in Identifiers:

| Identifier Type                                                                        | Identifier Type Description                                                                                                   | Implementation Note                       |
|----------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------|
| <b>If specimens were sent to CDC for testing, populate one of the two below fields</b> |                                                                                                                               |                                           |
| CDC Specimen ID (CSID)                                                                 | CDC specimen ID number.<br><br>Identifier Value Example format (10-digit number):<br>3000123456.                              | Located in ORC-3.1.1 of CDC's ELR message |
| Public Health Specimen ID                                                              | Public health laboratory specimen ID. Only use the public health specimen ID if this was sent to CDC along with the specimen. | Located in ORC-2.1.1 of CDC's ELR message |

- Would exist outside of the present lab workflow.
- Potential for inputting specimen ID specifically for CDC linkage if not transmitting through Lab.

# Poll 3 - Specimen ID



In Identifiers, should these specimen IDs be represented by one or two "Identifier Type" options?

- One
- Two

| Identifier Type                  | Data Element Description                                                               |
|----------------------------------|----------------------------------------------------------------------------------------|
| CDC or Public Health Specimen ID | CDC specimen ID number, or if not available, the public health laboratory specimen ID. |

| Identifier Type           | Data Element Description              |
|---------------------------|---------------------------------------|
| CDC Specimen ID           | CDC specimen ID number.               |
| Public Health Specimen ID | Public health laboratory specimen ID. |

# Poll 4 – Specimen ID Core



Should these specimen ID value(s) be part of the minimum value set for Identifiers?

- Yes.
- No - The repeating group should support them when needed, not core for all conditions.
- No - This repeating group should not support them.

| Identifier Type                  | Data Element Description                                                               |
|----------------------------------|----------------------------------------------------------------------------------------|
| CDC Specimen ID                  | CDC specimen ID number.                                                                |
| Public Health Specimen ID        | Public health laboratory specimen ID.                                                  |
| CDC or Public Health Specimen ID | CDC specimen ID number, or if not available, the public health laboratory specimen ID. |

# Birthing Parent-Infant Linkage



Is there a preferred method to be a “default approach” to standardize linkage between a maternal and an infant case?

## **Birthing parent's case ID/ national reporting jurisdiction (57% last call)**

- Often don't have the birthing parent's case ID if reported in another jurisdiction, easier to get info from interview.
- Is the info you need actually in the parent's case? What if the parent is not recognized as a case themselves?

## **Re-sending data elements from a birthing parent's case in the infant case notification (43% last call)**

- Ensures the information needed is present.
- May be less burden for low volume than for high volume conditions.
- Unable to analyze parental case info that is not explicitly asked for.
- What if there's a data entry error/ discrepancy if both methods used?

# Birthing Parent-Infant Linkage



Should these birthing parent - infant linkage data elements be considered part of core data for surveillance?

(Exactly 50-50 split on previous call.)

| Data Element (DE) Name                            | Data Element Description                                                                                 | Data Type |
|---------------------------------------------------|----------------------------------------------------------------------------------------------------------|-----------|
| Birthing Parent's Local Record ID                 | Provide the local record ID used for reporting birthing parent's case of this condition.                 | Text      |
| Birthing Parent's National Reporting Jurisdiction | Provide the national reporting jurisdiction used for reporting birthing parent's case of this condition. | Coded     |

Not listed as part of our minimum value set for identifiers, but the identifiers repeating group may still be used for this when it's thought to be appropriate for a condition.

# Next Steps



# Next Steps



Upcoming team meetings:

- **8/9 1-2pm ET – Laboratory**
- **8/16 1-2pm ET – Reporting Source**
- [Link to Sign Up](#)

ERU, SSCM, and Disability documents will go out to the wider DSWG soon.

The next large DSWG call will be August 30th, 1-2pm.